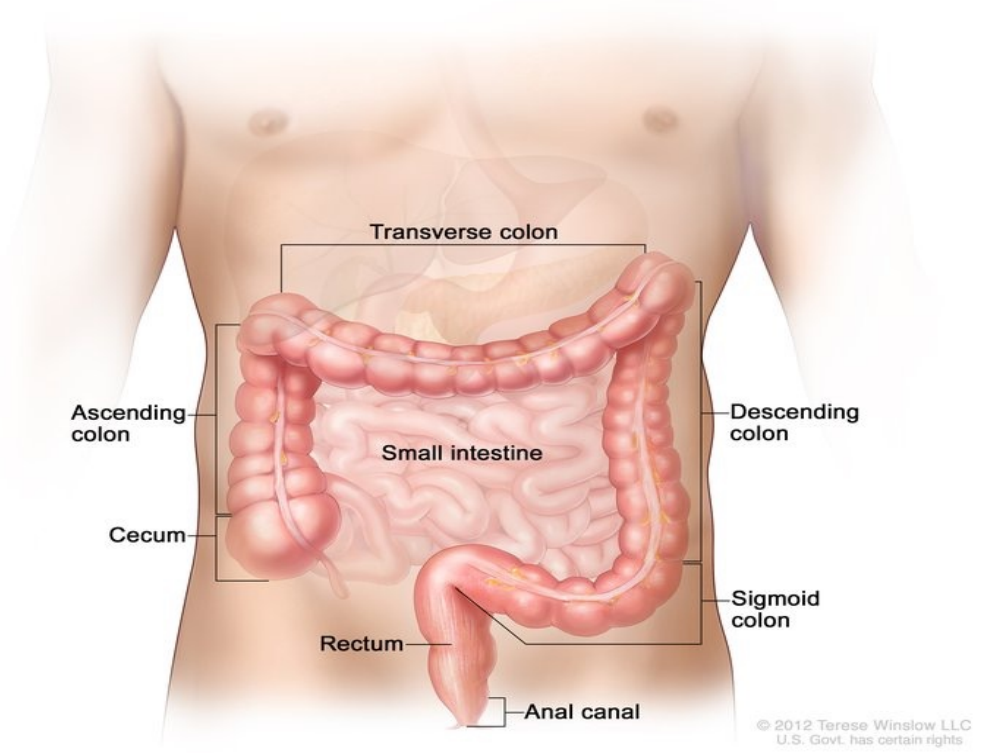
Southern Health and Social Care Trust



Lynsey Breen – IBD CNS



Topics for discussion

- The role of the IBD Nurse
- How we can support patients with IBD and support self management
- Flare management
- Medicines adherence
- IBD in pregnancy
- The IBD adviceline
- The future of IBD care



IBD clinical nurse specialist role

- Provide patient information, educational & support to new diagnosis
- Nurse led outpatient clinics including Biologic review clinics and see to start Biologics clinic
- Monitoring,checking medications and compliance
  - Organise & interpret bloods
  - Virtual pre-screening clinic
- 2 infusion clinics per week
  - 38-40 IBD patients receive biologic therapy in the DCC every week
  - Post infusion blood monitoring
  - Medication review

IBD clinical nurse specialist role

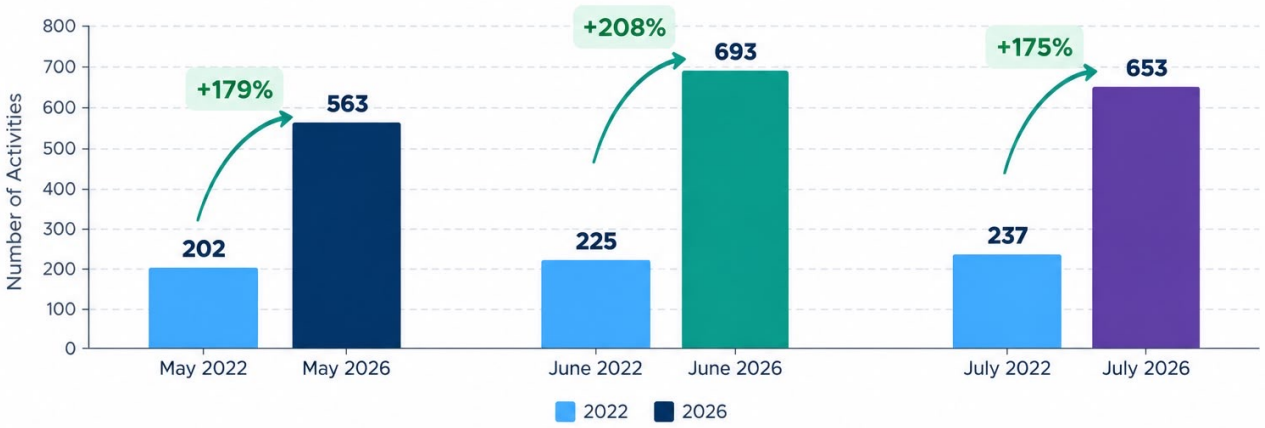
- Review of inpatients to help co-ordinate care received
- Education of patients on drugs to include monitoring effectiveness & side effects
- Management and optimisation of patients receiving sub cut biologic therapy
- Maintenance of an IBD database
- Blood monitoring
- Participation in MDT and acting as a patient advocate
- Working in partnership with primary care from diagnosis to support ongoing care and monitoring
- Facilitating the transition of young patients transferring from RVH aged >16 to the adults service

Monthly Activity Comparison

May – July 2022 vs May – July 2026

A significant increase in activity across all three months, with more than a threefold rise compared to 2022.

Overall increase
+208%
from May–July 2022
to May–July 2026



More than three times the activity
Activity increased by 179–208% across all months.

Consistent growth
Each month in 2026 shows a substantial increase compared to 2022.

Greater impact
This growth reflects increased demand, expanded services, or improved uptake.

Building on progress. Delivering more for the future.

- IBD adviceline (07788 726 875)
  - Operational Monday to Friday 9am to 10 am(excluding public holidays)
  - IDB nursing team will endeavor to answer the call within 24 to 48 hours as per IBD standards
  - The answer phone recording is clear, concise and request patients leave a contact number, date of birth and brief synopsis of the issue
  - For patients who are unable use the IBD helpline service they can either email ibdadviceline@southerntrust.hscni.net or text the helpline number
  - All calls, texts and emails are recorded electronically and auditable
  - Our colleagues from primary care are also invited to use this service to ensure treatments are initiated in a timely manner
  - The main aim of the adviceline is admission avoidance



Adviceline calls

Appropriate help line calls

- Patients flaring or experiencing new or worsening IBD symptoms
- Patients suffering undesirable side effects from IBD medication
- Questions around treatments, infections
- Delayed doses/missed doses of medications
- Planning a pregnancy/pregnancy related queries
- Travel related queries specifically regarding transportation of medications
- To request a dietician referral
- Sign posting to online support such as CCUK
- Education/support on the use/administration of topical therapies and how to self manage

Inappropriate help line calls

- Outside specified hours (9am to 10am)
- Patient with acute symptoms such as severe abdominal pain, distention, vomiting poor oral intake, fever or rigors, heavy or continuous rectal bleeding, chest pain or significant breathlessness.
- To amend or change appointments
- For medical advice unrelated to IBD
- For scan results /For blood results not requested by the IBD nursing team
- For prescribing of corticosteroids not initiated by our team
- For completing benefit applications such as PIP
- Patient's requiring surgical advice
- Prescribing of pain relief
- For referral to other specialities
- Patients who do not have a diagnosis of IBD but are under investigation

IBD Adviceline

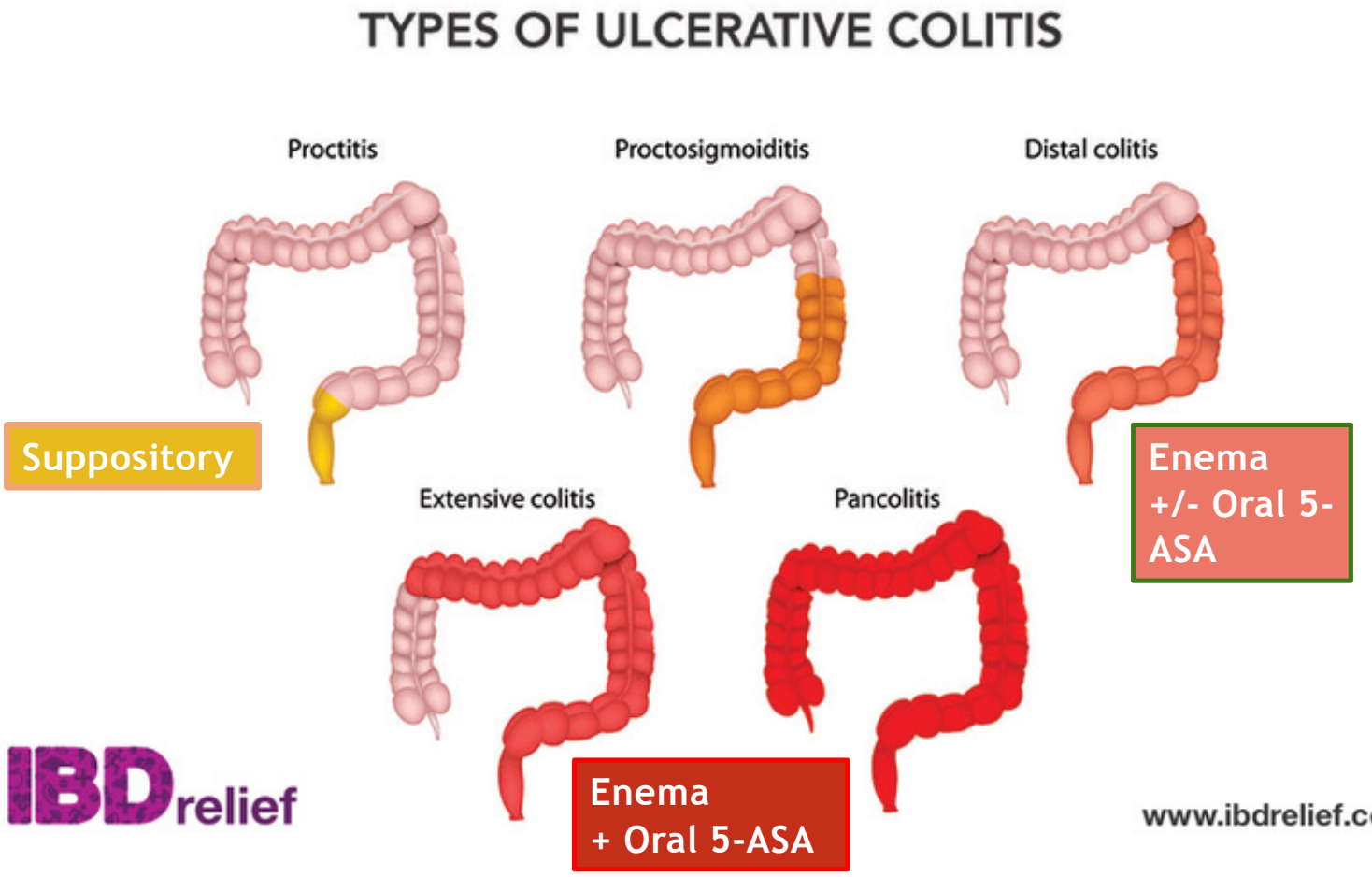
- Help line calls will be triaged – priority given to patients flaring
- IBD nursing team will conduct a record review to confirm diagnosis, disease location, previous flares, surgical history and complications. They will also review recent laboratory and diagnostic results. This preparation enables a more focused and informed conversation with the patient
- Checking current treatment including any recent changes/dose intensification
- They will check previous contact with the IBD adviceline and advice provided
- The IBD nursing team will assess symptoms based on the proceeding 24 hours to establish disease activity and identify signs of deterioration. They usually will ask the following questions
- Stool frequency/consistency/blood/mucus/severity/duration
    - Any urgency/incontinence/tenesmus/difficulty passing motions
    - Any abdominal pain
    - Change in appetite
    - weight loss
    - Any EIM'S Any other problems such as fevers/abscesses/vomiting
    - Current medication, name/dose/frequency
    - Travel history/recent antibiotic therapy

IBD Adviceline

- Check compliance never assume that medications are being taken simply due to prescriptions being reordered ask patients and be direct
- Check dosage of medication taken does it reflect their current prescription
- Check treatments are being used correctly in particular rectal therapy re educate patients as required including providing visual aids
- Arrange up to date bloods to include FBC, CRP, U&E, FBC
- Consider stool samples and what is clinically appropriate such as o&s, clostridium difficile, FCP
- Always consider patient safety and ensure urgent escalation refer to ED if necessary
- Arrange for review in nurse led clinic if further education/support would be beneficial to the patient

Ulcerative Colitis

- Large intestine only
- Distribution:
  - Proctitis – rectum only
  - Left sided colitis / distal colitis
  - Pan colitis
- Distribution helps to determine treatment options
  - Distal disease = topical therapies
  - More proximal disease = oral therapies (+/- topical)


TYPES OF ULCERATIVE COLITIS
Proctitis
Proctosigmoiditis
Distal colitis
Suppository
Enema
+/- Oral 5-ASA
Extensive colitis
Pancolitis
Enema
+ Oral 5-ASA
IBDrelief
www.ibdrelief.com



Ulcerative colitis first line management

- 5 Aminosalicylic acid (5ASA)
- Oral and rectal

They work by helping to ease inflammation in the bowel, by allowing damaged tissue to heal. Ultimately the goal is to achieve and maintain remission improving a patient's quality of life

Dosage

Octasa Maximum treatment 4.8 grams in divided doses

Maintenance treatment 2.4 grams daily

Pentasa maximum treatment dose 4 grams daily

Maintenance 2grams daily

Salofalk Maximum treatment dose 3 grams daily

Maintenance dose 1.5 grams daily

Mezevant XL treatment dose 4.8 grams daily

Maintenance dose 2.4 grams daily

Mesalazines / 5-ASAs

Mesalazines / 5-ASA - ORAL

Patients with Ulcerative Colitis will usually be prescribed one of these preparations. There are several brands of Mesalazine - Each has a different dose and each releases differently in the bowel. There are two doses 'maintenance' when you don't have symptons and 'treatment' when you do. It's perfectly safe for you to increase your Mesalazine therapy to 'treatment' when you have symptons (as indicated in the flare section) but if you do, we ask that you increase therapy for 6 weeks. Some patients may need to stay on the treatment dose.

If you have not seen a definite improvement in your symptoms within 7 to 14 days please contact your IBD Specialist Team

Pentasa

Granules/tablets
Treatment is 4grams once a day.
Maintenance is 2grams once a day.

Salofalk

Granules/tablets
Treatment is 3grams once a day.
Maintenance is 500mg 3 times daily.

Octasa

Treatment is 4.8grams in divided doses.
Maintenance is 1.2 - 2.4grams once a day or in divided doses.

Asacol

Tablets
Treatment is 4.8grams in divided doses.
Maintenance is 1.2 - 2.4grams once a day or in divided doses.

Mezavant XL

Tablets
Treatment is 4.8grams once a day.
Maintenance is 2.4gram once a day.

Mesalazine / 5-ASA – Rectal

Mesalazine Suppositories and Enemas. If you have a supply of these and are familiar with how to use them, it is safe to start these, normally nightly for two weeks, to help control symptoms.
Symptoms should improve after a week or two, but if they don't get in touch with your IBD Specialist Team.

Pentasa

Suppository
Treatment is 1g once a day for 4 weeks
Enema
Treatment is 1g once a day for 4 weeks

Salofalk

Suppository
Treatment is 1g daily

Enema liquid
Treatment is 2g once a day

Enema Foam
Treatment is 1-2g once a day

Distribution and treatment of Crohn's

Crohn's can affect anywhere from the mouth to anus

Approx. 2/3 of Crohn's disease is localised to the terminal ileum

5ASA not recommended/effective

Immunomodulators such as azathioprine or mercaptopurine may help/maintain remission

They are not suitable for everyone therefore TPMT levels re required pre-initiation to ensure that this is a viable treatment option

Requires ongoing blood monitoring as per the shared care guidelines

Azathioprine affects how the immune system works therefore patients are more likely to get infections



Ulcerative colitis when is hospital admission required?

- > 6 bowel motions daily, plus 2 or more of the following
- Visible blood in stool
- Pyrexia > 37.8 °c
- Pulse > 90bpm
- Anaemia (HB< 105)

Crohn’s disease
when is hospital admission required?

- Tachycardia
- Vomiting
- Severe abdominal pain
- Signs of perianal abscess formation
- Obvious signs of obstruction (vomiting, severe abdominal pain, fever)
- Palpable mass
- On maximum outpatient treatment

Advanced therapies

- Biologics may be prescribed for patients with Crohn's and ulcerative colitis that haven’t responded to other treatments
- Escalation of treatment is usually required if 2 or more courses of oral corticosteroids are required within a 12-month period
- Infliximab is licensed for Use as rescue therapy in acute severe colitis
- Treatment may be oral IV, or by sub cutaneous injection dependant on drug chosen
- Live vaccines are contraindicated

Pregnancy in IBD

- Patients are encouraged to contact us if planning a pregnancy or should they become pregnant
- Primary goal is to ensure their IBD is stable prior to conception and ultimately keeping it under control throughout their pregnancy journey. Experiencing a flare during pregnancy increases the risk of pregnancy complications
- Continue medications with the exceptions of JAK inhibitors, methotrexate (list subject to change). Patients are advised not to become pregnant due to the risk of foetal abnormalities (patients are advised to use suitable contraception to prevent pregnancy)
- Patient are educated at clinic to ensure they use effective contraception if they do not want to get pregnant Biologics are also sometimes held in the third trimester if the patient is stable however these decisions are made jointly with their consultant at clinic
- If a mother is on biologics during pregnancy. No live vaccines must be given to the baby for the first year. Additionally, mothers should not receive live vaccines
- Some IBD medications may affect male fertility



:CUK Pregnancy & Birth



CCUK e Health & Fertility

Partnership working

- Ultimately IBD is a long-term chronic condition, and patients must be educated in self-management of their condition
- Better communication between primary and secondary care
- GP/pharmacist to inform us, if possible, patient's who are repeatedly requesting/needing steroids for their IBD as this indicates treatment failure
- Regular medication reviews by healthcare professionals to identify noncompliance with prescribed treatment such as 5ASA therapy. As we need to Identify barriers and potential solutions
- GP could consider providing patients with a rescue pack of 5ASA therapy so they can initiate self management in keeping with the IBD Flare card to avoid unnecessary delays and deterioration in symptoms
- IBD team to provide support to GP's by providing clear channels of communication such as IBD adviceline email, IBD adviceline contact details
- The IBD team aims to work in partnership with our GP colleagues and GP pharmacists to empower our patients to take control of their condition to ensure the long-term sustainability of the IBD service provision



The future of our service provision

- Patient initiated follow up (PIFU)
- Proactive rather than reactive management
- Ambulatory care to prevent unnecessary hospital assessment
- Workforce development
- Digital & remote care such as home FCP testing and remote consultations

